

The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children

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Summary

Background Peanut-allergic patients are affected by a condition which forces them and their families to exercise extreme dietary vigilance and experience constant uncertainty throughout their lives.

Objective To compare the quality of life and family relations of children and adults with a peanut allergy to that of children and adults with a rheumatological disease.

Methods Patients with a confirmed diagnosis of peanut allergy or a rheumatological disease completed (for children less than 18 years, by proxy) self-report questionnaires regarding the impact of their condition on their quality of life and family relations. A vertical visual analogue scale and the Impact on Family Questionnaire (IFQ) served as outcome measures.

Results One hundred and fifty-three peanut-allergic children were compared with 69 children with a rheumatological disease while 37 peanut-allergic adults were compared with 42 adults with a rheumatological disease. The parents of peanut-allergic children, compared to the parents of children with a rheumatological disease, reported that their children had significantly more disruption in their daily activities. Furthermore, the parents of peanut-allergic children reported more impairment in the familial-social dimension of the IFQ. Conversely, adults with a chronic rheumatological disease reported more disruption in their family relations than peanut-allergic adults.

Conclusion Given the considerable disruption in daily activities and family relations reported by the parents of peanut-allergic children, accurate diagnosis of peanut allergy is essential. Our work should make health care professionals dealing with children with confirmed peanut allergy more aware of the support that these families may require. Furthermore, we hope to motivate food industries to offer more 'peanut free' products to decrease the dietary restrictions of these patients while minimizing their potential for accidental ingestion.

Keywords: peanut allergy, quality of life, family relations, children, adult, rheumatological disease

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Introduction

Peanut allergy is a common food allergy with a prevalence in the United States and the United Kingdom estimated

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between 0.4 and 0.7% [1,2]. Once diagnosed, it tends to last lifelong [3]. It is the most common cause of fatal food-related anaphylaxis [4,5]. As accidental ingestion of even minute quantities of peanut [6] by a peanut-allergic individual can immediately provoke life-threatening symptoms, patients must maintain strict avoidance. However, owing to the frequent use of peanut-based products in common foods, complete avoidance is difficult and accidental ingestions are frequent [3,7,8]. Most peanut-allergic individuals who have experienced severe allergic reaction have done so by unknowingly ingesting peanut-containing foods [4,5].

Peanut-allergic patients and their families must exercise extreme dietary vigilance to avoid preventable peanut exposure. However, they continue to experience constant uncertainty throughout their lives regarding the risk of accidental ingestion. In our clinical practice, we have observed that families experience considerable anxiety related to the diagnosis of peanut allergy. It is anticipated that the frustration from avoidance of numerous food products, many of which seem unrelated to peanut, but cannot be guaranteed absolutely peanut free, combined with the fear of accidental ingestion, lead to significant psychological distress and social restrictions, compromising patient and family well-being. Although not causing physical disability like many chronic conditions, it is likely that peanut allergy affects quality of life and family relations.

Despite intense and increasing public and medical interest, the effect of peanut allergy on the quality of life of patients and their families has never been evaluated. The objective of this study was to evaluate the impact of peanut allergy on quality of life and family relations experienced by peanut-allergic individuals and their families and to compare it with the impact of chronic rheumatological diseases. Children with rheumatological diseases and particularly those with juvenile rheumatoid arthritis have been shown to have significant impairment in functional status [9] likely due to ongoing disease activity [10]. More recently, attempts have been made to develop instruments to document outcome in a quantitative fashion and thus provide an overall measure of the child's quality of life [11,12]. The particular difficulties associated with such measurements have recently been emphasized [13,14], but available evidence suggests significant impairment [15]. Adults [16,17] with rheumatological diseases have also been shown to have substantial impairment in quality of life owing to the pain, fatigue, physical limitations, and psychological distress they experience. Although the impairment in quality of life and family relations would arise for very different reasons in those with peanut allergy and rheumatological diseases, we hypothesized that it would be of similar magnitude. Patients with other chronic diseases such as inflammatory bowel disease or diabetes would also have been appropriate controls, but our easy access to a

paediatric and adult population with chronic rheumatological conditions motivated our choice.

Subjects and methods

This study compared children (defined as less than 18-year-old) and adult patients (18–45-year-old) with a confirmed diagnosis of peanut allergy to those with a confirmed diagnosis of a rheumatological disease. For both groups, age at recruitment was limited to less than 46 years to minimize the presence of comorbidity. Adult patients in both groups completed self-reported questionnaires on the impact of their condition on their quality of life and family relations. For children, the parent or guardian was asked to complete the questionnaires. Therefore, the responses expressed parental opinion about the impact of their child's condition on his/her quality of life and on family relations. Questionnaires assessing demographics, global health, presence of nonatopic comorbidities and presence and severity of asthma were also completed. For the peanut-allergic group, characteristics of the first allergic reaction to peanut and presence of other atopic conditions were also elicited.

Identification of peanut-allergic and rheumatological disease participants

Three hundred and seventy-six potential peanut-allergic patients (290 children, 86 adults) were identified through four approaches:

- Reviewing charts of patients referred to the allergy clinics of the Montreal Children's Hospital or the Montreal General Hospital between January 1993 and December 1997 (76% of total number of potential peanut-allergic children approached, 70% of adults approached);
- Consecutive peanut-allergic patients presenting to the allergy clinics of the Montreal General Hospital from January 1998 to October 1998 (6% of adults);
- Advertising through a lay educational/support organization, l'Association Québécoise des Allergies Alimentaires (24% of children, 13% of adults) and;
- Newspaper advertisements (12% of adults).

Potential participants identified in these ways were sent a letter explaining the study and the questionnaires. Persons included in the study had symptoms consistent with an allergic reaction (rhino-conjunctivitis, urticaria, angioedema, breathing difficulties, gastro-intestinal manifestations or loss of consciousness) occurring less than 4 h after an unequivocal exposure to peanut and had either a positive skin prick test or serum-specific IgE to peanut. The charts from the Montreal General Hospital and the Montreal Children's Hospital, supplemented by additional information from the treating physician where applicable, as well

as the patient self-report questionnaires concerning peanut allergy, were reviewed by a single investigator (MNP) to ascertain patient eligibility. Persons with a pre-existing rheumatological disease were excluded.

Potential participants with a chronic rheumatological disease were consecutive clinic attendees at the immunology/rheumatology clinics of the Montreal Children's Hospital (202 children) or the Montreal General Hospital (70 adults) between June 1997 and October 1998. The majority (76%) of the adult participants had a diagnosis of Systemic Lupus Erythematosus, according to the criteria of the American College of Rheumatology (ACR) [18]. The majority (74%) of the child participants had juvenile rheumatoid arthritis according to ACR criteria [19]. For individuals with other diseases (e.g. spondyloarthritis, Reiter's disease, dermatomyositis), the diagnosis was confirmed by their immunologist or rheumatologist, either according to the criteria of the ACR [20–23] where applicable or according to generally accepted clinical criteria [24,25]. A letter explaining the study and the questionnaires was mailed to all eligible participants. People reporting any food allergy were excluded from the study.

Questionnaires

To quantify the impairment in quality of life, we used a vertical visual analogue scale (VAS) adapted from the European Quality of Life questionnaire (EuroQoL-5D) [26]. Participants were asked to grade on the scale how much disruption they experienced in their daily activities due to their peanut allergy (for the peanut-allergic group) or as a result of their illness (for the rheumatological disease group). The scale was anchored from 0 (no disruption) to 100 (most disruption imaginable). For the paediatric population, the parent/guardian was asked to indicate: 'How much disruption does your child experience in his/her daily activities because of his/her peanut allergy/illness?'

To evaluate the impact of peanut allergy or a rheumatological disease on the family, we used the Impact on Family Questionnaire (IFQ) [27]. This questionnaire has been used to assess the impact of chronic childhood conditions such as eczema, diabetes, spina bifida, ventilator dependence, post traumatic brain injury and behavioural disturbance [28–32]. Respondents graded on a scale, ranging from 1 to 4 (1 = strongly agree, 4 = strongly disagree), their agreement with 24 specific statements relating to four dimensions of family life:

- Familial/social — the disruption in normal social interaction both within and outside the family system as a direct consequence of the illness (e.g. 'people in the neighbourhood treat us specially because of my child's

illness/peanut allergy' and 'we see family and friends less because of the illness/peanut allergy');

- Personal strain—the personal dysequilibrium experienced by the patient or the primary caregiver of the patient as a result of the psychosocial burden of the illness (e.g. 'nobody understands the burden I carry' and 'fatigue is a problem for me because of my child's illness/peanut allergy');
- Financial Burden — the economic consequences for the family owing to the presence of an ill individual;
- Mastery — the coping strategies employed by the family to master the stress of the illness (e.g. 'learning to manage my child's illness/peanut allergy has made me feel better about myself' or 'because of what we have shared we are a closer family').

Items in the first three subscales are reverse coded, i.e. 1 = 4. The four subscores are an arithmetic sum of the respective items. Higher scores in the familial/social, personal strain and financial burden dimensions indicate a more negative impact on the family. A higher score in the mastery subscale indicates less mastery of stress due to the disease. Because the IFQ was originally developed for childhood illness, questions were modified to apply to peanut-allergic patients by substituting 'peanut allergy' for 'illness' (as indicated in the example questions) and two items were deleted because they were not applicable to an adult population (i.e. 'it is hard to find a reliable person to take care of my child' and 'we try to treat my child as if he/she were a normal child').

All patients completed either the Child Health Questionnaire (CHQ) [33] or the Medical Outcomes Study Short Form 36 (SF-36) (for adults) [34] as an assessment of global health status. The physical component summary score of each of these questionnaires was used to characterize the physical disabilities of patients (higher score indicating more physical disability). For both of these summary scores, US population norms are available.

Co-morbid nonatopic conditions were assessed through participant self-response to a list of illnesses based on the most frequently reported conditions in the Beaver Dam Study, a longitudinal cohort study of health status and health-related quality of life for a random sample of adults in Beaver Dam, Wisconsin [35,36]. Co-morbidities were modified for children by adding attentional or behavioural problems, developmental delay, and speech problems using the comorbidity list from the CHQ [33]. Patients were also asked to report any other significant diseases (e.g. chronic thyroid disease, chronic renal disease) that were not included in the list of comorbidities.

Patients who considered themselves asthmatic answered a questionnaire designed to categorize asthma severity into mild, moderate or severe, according to the Canadian Consensus Guidelines for the Management of Asthma [37].

Determination of the severity of the first allergic reaction to peanut was based on patient self-report of the characteristics of the reaction. The reaction was considered mild if it involved rhino-conjunctivitis or an urticarial or erythematous rash; moderate if facial swelling, throat tightness or itchiness, vomiting, abdominal pain or breathing difficulty (other than wheeze) occurred and severe if wheeze, cyanosis or loss of consciousness were reported. Other atopic conditions were assessed by querying peanut-allergic patients on the presence of allergic rhinitis, urticaria, eczema and other food allergies.

French Canadian versions of all questionnaires developed by translation and back translation were provided to French Canadian patients [38].

Statistical analysis

Children and adults were analysed separately. Data on demographics, disease characteristics, and global health status are expressed using means, standard deviations and proportions (where appropriate). To compare the five major outcomes (VAS and four dimensions of the IFQ) between the peanut-allergic and rheumatological disease groups, unadjusted means and 95% confidence intervals are first presented. Adjusted mean differences between groups and 95% confidence intervals are then presented for the major outcomes.

To develop adjusted mean differences, multivariate regression models were developed for each of these outcome variables. Candidate independent variables included an indicator variable for the disease group, i.e. peanut allergy or rheumatological disease. The estimated coefficient for this indicator variable expresses the adjusted mean difference between disease groups. Other potential independent variables in the regression models included age, sex, parent's or adult participant's education level (categorized as attaining a high school diploma, college degree, or university degree), disease duration, presence and severity of asthma, number of other nonatopic comorbidities, presence of cancer, presence of diabetes, and presence of atopy. It should be noted that for the rheumatological disease group, the presence of atopy was based only on the presence of asthma or chronic sinus trouble as the questions relating to other atopic conditions, i.e. allergic rhinitis, urticaria, and eczema, were posed only to the peanut allergy group. Model selection was based on Bayes Factors as approximated by the Bayesian Information Criterion (BIC) [39]. Models selected by the BIC have been shown to have better prediction properties on average compared to other model selection algorithms such as backward or forward stepwise procedures [39].

Results

After one reminder letter, 343 (53%) of the 648 questionnaires were returned. The response rate was 58% for peanut-allergic children, 57% for peanut-allergic adults, 39% for children with a chronic rheumatological disease and 67% for adults with a chronic rheumatological disease. After the questionnaires were reviewed, 42 were excluded because they did not meet the inclusion criteria; therefore a total of 301 questionnaires was analysed. Table 1a shows the characteristics of each subgroup that participated. The parents of peanut-allergic children reported the first peanut-allergic reaction occurred at a mean age of 1.7 years, consistent with other reports [8,40]. Adults reported their first reaction occurring at a mean age of 10.1 years with a median age of 6 years. There was a high frequency of other atopic conditions and other food allergies in the peanut-allergic group and a high frequency of comorbidities in the chronic rheumatological disease group. Although we accepted reactions occurring within 4 h after ingestion of peanut as compatible with peanut allergy, 95% of patients described signs and symptoms within 1 h of peanut ingestion (data not shown). Eighty-two percent of the parents of peanut-allergic children and 64% of the parents of rheumatological disease children had received some post-secondary education. Ninety-two percent of the peanut-allergic adults and 67% of the rheumatological disease adults had received postsecondary education. Table 1b shows the characteristics of the nonrespondents.

Table 2 presents the scores of the VAS and the four dimensions of the IFQ for the children. The original IFQ article [27] provides descriptive statistics for each of the four subscales of the IFQ. The mean scores for the familial/social, personal strain, financial burden, and mastery subscales were 22.09, 16.62, 10.37, and 9.95, respectively. Most of these scores exceed those reported by the parents of either the peanut-allergic or rheumatological disease children where the highest mean score for each subscale was 18.3, 12.7, 8.7, and 10.4, respectively. However, the original sample was composed of the urban poor from New York City and is therefore not comparable to our patient population. There is only one other article providing scores for the individual subscales [41]. For mothers of children with long-term tracheostomy [41], the mean scores on the familial/social, personal strain, financial, and mastery subscales were 20.5, 14.2, 10.2, 7.9, respectively. There are no other published articles detailing scores for each of the four dimensions, but rather a total score representing the sum of the four subscales which denotes the overall negative impact of the condition. For children with diabetes [28], mild eczema [28], ventilator dependent children [30], and children 1 month post-traumatic brain injury [31], the mean total

Table 1a. Characteristics of respondents

| | PA children | RD children | PA adults | RD adults |
|---|-------------|-------------|-------------|-------------|
| Sample size | 153 | 69 | 37 | 42 |
| % of females | 40 | 74 | 68 | 93 |
| Mean age, year (sd) | 6.4 (4.0) | 10.4 (4.1) | 30.9 (9.4) | 35.4 (7.4) |
| Mean disease duration, year (sd) | 4.7 (3.7) | 4.6 (2.8) | 20.2 (11.4) | 9.0 (5.8) |
| Mean CHQ/SF-36 physical summary score* (sd) | 50.5 (7.5) | 42.4 (14.8) | 48.6 (9.0) | 41.2 (12.8) |
| — proportion below population average† | 62% | 75% | 54% | 74% |
| Age at first peanut-allergic reaction, year (sd) | 1.7 (1.5) | N/A | 10.1 (10.2) | N/A |
| Severity of first peanut-allergic reaction (%) | | | | |
| Mild | 27 | N/A | 12 | N/A |
| Moderate | 55 | | 61 | |
| Severe | 18 | | 27 | |
| % with other atopic conditions‡ | 88 | 23 | 92 | 17 |
| % with asthma | 61 | 20 | 68 | 14 |
| Severity (%) | | | | |
| Mild | 38 | 64 | 52 | 50 |
| Moderate | 51 | 22 | 48 | 33 |
| Severe | 11 | 14 | 0 | 17 |
| % with eczema | 57 | N/A | 35 | N/A |
| % with allergic rhinitis | 36 | N/A | 68 | N/A |
| % with other food allergies§ | 59 | N/A | 86 | N/A |
| % with nonatopic comorbidity(ies) | 31 | 55 | 62 | 83 |
| % of parents or adults with postsecondary education | 82 | 64 | 92 | 67 |

*Child Health Questionnaire (CHQ) not validated for children <5 years. Although the CHQ is not validated for children <5-year-old, it was completed by the parents of all children by asking them to omit the 'self-esteem' section and a single item in the 'getting along' section which were not considered to be applicable to children <5 years. Among the PA children, 84 were ≥5 years and among the RD children, 61 were ≥5 years. However, if children <5 years were included by imputing the mean score on the completed CHQ items for the items not completed because not considered relevant for those <5 years, the mean (sd) CHQ score for the PA children was 51.4 (7.6) and for the RD children 42.8 (14.6). When all children are included, 53% of PA children were below the population average and 75% of RD children were below the population average. †General population norm for children: Child Health Questionnaire Physical Summary Score = 53.2 (33); general population norm for adults: SF-36 Physical Component Score = 50 (34). ‡For PA groups, 'other atopic conditions' refers to asthma, eczema, allergic rhinitis, or hives; for RD groups, it refers to asthma or chronic sinus trouble. §Not applicable to RD groups because presence of food allergy(ies) was an exclusion criterion. PA, Peanut-allergic; RD, Rheumatological Disease.

Table 1b. Characteristics of non-respondents

| | PA children | RD children | PA adults | RD adults |
|--|-------------------------|---------------------------|--------------------------|---------------------------|
| Sample size | 121 | 124 | 37 | 23 |
| % of females | 41 <i>n</i> * = 120 | 69 <i>n</i> = 121 | 58 <i>n</i> = 36 | 87 <i>n</i> = 23 |
| Mean age, year (sd) | 8.2 (4.8) <i>n</i> = 91 | 12.1 (4.0) <i>n</i> = 122 | 26.1 (5.6) <i>n</i> = 12 | 33.4 (6.8) <i>n</i> = 21 |
| Mean disease duration, year (sd) | 4.7 (3.8) <i>n</i> = 81 | 5.2 (3.2) <i>n</i> = 113 | 18.5 <i>n</i> = 1 | 9.0 (6.3) <i>n</i> = 21 |
| Mean SF-36 summary score (sd) | N/A | N/A | N/A | 41.8 (11.2) <i>n</i> = 18 |
| Proportion below population average | | | | 67% |
| Age at first peanut-allergic reaction, year (sd) | 2.7 (2.4) <i>n</i> = 82 | N/A | 11 <i>n</i> = 1 | N/A |
| Severity of first peanut-allergic reaction (%) | <i>n</i> = 87 | N/A | <i>n</i> = 7 | N/A |
| Mild | 45 | | 14 | |
| Moderate | 53 | | 57 | |
| Severe | 2 | | 29 | |
| % with other atopic conditions† | 88 <i>n</i> = 84 | N/A | 92 <i>n</i> = 12 | N/A |
| % with asthma | 58 <i>n</i> = 84 | N/A | 75 <i>n</i> = 12 | N/A |
| % with eczema | 49 <i>n</i> = 84 | N/A | 25 <i>n</i> = 12 | N/A |
| % with allergic rhinitis | 26 <i>n</i> = 84 | N/A | 50 <i>n</i> = 12 | N/A |
| % with other food allergies | 65 <i>n</i> = 83 | N/A | 58 <i>n</i> = 12 | N/A |

*In each cell, *n* = number of nonrespondents with data available; †other atopic conditions refers to asthma, eczema, allergic rhinitis, or hives.

Table 2. Mean outcome scores for children

| | PA unadjusted mean (95% CI) | RD unadjusted mean (95% CI) | Adjusted mean difference* (95% CI) |
|---|--------------------------------|--------------------------------|---------------------------------------|
| VAS, range 0 (no disruption) — 100 (most disruption) | 37.3 (33.3, 41.3) | 25.9 (19.6, 32.1) | 14.05 (6.66, 21.44) |
| IF — familial/social, range 9–36 (greater negative impact) | 18.3 (17.5, 19.1) | 14.3 (13.0, 15.6) | 3.38 (1.77, 4.99) |
| IF — personal strain, range 6–24 (greater negative impact) | 12.7 (12.2, 13.3) | 12.0 (10.9, 13.0) | 0.85 (–0.29, 1.99) |
| IF — financial burden, range 4–16 (greater negative impact) | 7.4 (6.9, 7.8) | 8.7 (8.0, 9.5) | –1.13 (–1.94, –0.32) |
| IF — mastery, range 5–20 (less mastery of stress) | 9.9 (9.6, 10.2) | 10.4 (9.7, 11.1) | –0.68 (–1.35, –0.02) |

*Refers to the mean difference between the two groups after controlling for important patient covariates; see statistical analysis for details. PA: peanut-allergic; RD: rheumatological disease; VAS: Visual Analogue Scale; IF: Impact on Family Questionnaire.

score on the IFQ was 44.4, 47.28, 50, and 35.4, respectively vs a mean total score of 48.3 and 45.4 for the peanut-allergic and rheumatological disease children, respectively. Peanut-allergic children and their families therefore experience significant disruption in their daily activities and in their family relations.

After adjusting for confounding variables, peanut-allergic children had significantly more disruption (difference of 14.0 points) in their daily activities than children with a rheumatological disease. With respect to family relations, peanut-allergic children and their families also experienced significantly more disruption in their familial–social interactions (difference of 3.4 points). On the personal strain subscales, the groups did not differ while on the mastery subscale, the families of peanut-allergic children scored minimally lower, suggesting they were slightly more effective in coping with the stress imposed by their condition. On the financial burden subscale, children of the rheumatological disease group had significantly higher scores (difference of 1.1 points) than those of the peanut-allergic group, indicating greater economic difficulties.

Results for the adult groups are presented in Table 3. Peanut-allergic adults had a lower score on the VAS

(difference of 3.9 points), but the confidence interval did not exclude the possibility of a clinically interesting effect in either direction. Peanut-allergic adults experienced less familial/social disruption (difference of 4.0 points), less personal strain (6.2 points) and less financial burden (3.6 points) than adults with a rheumatological disease. On the mastery subscale, peanut-allergic adults scored higher (2.4 points) than adults with a rheumatological disease, suggesting they were less effective in developing coping skills to manage their peanut allergy than adults with a rheumatological disease.

Discussion

We evaluated the quality of life and family relations of children and adults with a peanut allergy and compared it to that of children and adults with a rheumatological disease. In our sample, we showed that the parents of peanut-allergic children believed that their children had difficulties in many areas. Their children had more impairment in their quality of life and their family experienced more disruption in the familial/social dimension of family relations compared with parents of children with

Table 3. Mean outcome scores for adults

| | PA unadjusted mean (95% CI) | RD unadjusted mean (95% CI) | Adjusted mean difference* (95% CI) |
|---|--------------------------------|--------------------------------|------------------------------------|
| VAS, range 0 (no disruption) — 100 (most disruption) | 34.8 (24.6, 44.9) | 39.2 (30.6, 47.9) | –3.87 (–17.22, 9.48) |
| IF — familial/social, range 9–36 (greater negative impact) | 14.2 (12.3, 16.0) | 18.4 (16.9, 19.9) | –4.03 (–6.40, –1.66) |
| IF — personal strain, range 5–20 (greater negative impact) | 9.8 (8.7, 10.9) | 15.1 (13.9, 16.3) | –6.17 (–7.72, –4.62) |
| IF — financial burden, range 4–16 (greater negative impact) | 5.4 (4.8, 6.0) | 9.1 (8.2, 10.0) | –3.63 (–4.72, –2.54) |
| IF — mastery range 4–16 (less mastery of stress) | 12.1 (11.1, 13.1) | 9.8 (9.2, 10.5) | 2.41 (1.20, 3.61) |

*Refers to the mean difference between the two groups after controlling for important patient covariates; see statistical analysis for details. PA: peanut-allergic; RD: rheumatological disease; VAS: Visual Analogue Scale; IF: Impact on Family Questionnaire.

a rheumatological disease. In contrast to children, adults with peanut allergy have comparable disruption in their quality of life but less disruption in family relations compared to adult rheumatological patients; however, a few peanut-allergic adults experienced considerable disruption (data not shown).

In peanut-allergic children, parental perception of the considerable disruption in their children's daily activities and the impairment in familial/social interactions is due to their children's risk of death. The dietary restrictions they must ensure are enforced to minimize this risk represent a means for parents to achieve mastery over the condition. However, the loss of parental mastery when someone else cares for the child creates substantial parental burden. Some parents even refuse to allow their peanut-allergic children to participate in situations such as birthday parties, school lunches and school excursions.

For both the adults and the children, the financial burden was higher for the rheumatological disease group. This is understandable given that this condition likely leads to greater use of medical resources.

The mastery subscale evaluates if the participants developed coping strategies to live better with their condition. Our findings suggest that parents of peanut-allergic children tend to have slightly more mastery over the stress due to their child's allergy while peanut-allergic adults have less mastery over the stress due to their condition. Adults are usually much more compulsive about managing their children's allergies than their own. Our experience is that they tend to carry their auto-injectable adrenaline less often than children. Therefore, the higher levels of stress in families of peanut-allergic children leads to better coping strategies which likely entails some degree of family disruption. Adults, who may be complacent about their own allergies, exercise less caution and therefore feel less in control of their problem. The increased concern expressed by adults for their children rather than themselves, albeit stressful, may also be beneficial.

The physical summary score of the CHQ and SF-36 reflected the physical disability of the participants and showed that our sample of individuals with rheumatological diseases had significant physical disabilities. Even considering this, the disruption experienced by peanut-allergic children and their families exceeded that of children with rheumatological diseases.

The questionnaires we used reflected the parental perspective. Although studies have demonstrated that parents can serve as reliable proxies for their children in evaluating physical [42,43] and emotional [44] constructs in juvenile arthritis, it would nevertheless be of interest to incorporate a questionnaire completed by the children themselves to measure their perception of impairment in their quality of life. Furthermore, we recognize that by assessing the

disruption in daily activities experienced by patients, we may not be measuring all factors influencing health-related quality of life. However, in the absence of any other previously developed instrument that can be applied to both peanut allergy and rheumatological diseases, we believed that the visual analogue scale provides some measure of quality of life. Although the IFQ has not been formally validated for adults, we desired a questionnaire which would allow results between parents and adult participants to be compared. We anticipated that the family dimensions influenced by having a peanut-allergic (or rheumatological disease) child would be somewhat similar to those affected by having the condition itself. Hence, we believed the questionnaire was appropriate to apply to adults.

A limitation of the study is the potential sample bias resulting from the volunteer completion of the questionnaires. With an overall response rate of 53%, it is possible that those who were more likely to participate felt their condition had a considerable negative impact on their life. However, we believe that this would apply to both study groups. Therefore, the low response rate should not have influenced our conclusions regarding between-group differences. It may have resulted in overstatement of the impairment of the general population of individuals affected by these conditions, but nevertheless when we compared respondents with nonrespondents, we observed little difference in demographic and disease characteristics. Among the rheumatological disease adult participants, 74% had a physical summary score less than the general population norm, whereas among the nonparticipants, 67% scored less than the norm. Among the peanut-allergic children, more participants experienced a severe first reaction than nonparticipants (18% vs 2%), whereas among the peanut-allergic adults, comparable percentages of participants and non participants reported a severe reaction (27% vs 29%). Peanut-allergic child and adult participants and nonparticipants reported comparable frequencies of moderate reactions.

Another possible sample bias results from the recruitment of some subjects from a community organization for people with food allergy. Members of these organizations are self-selected and may have more difficulty in coping with their condition than the general peanut-allergic population. Alternatively, they may find support and ways to manage their condition with the help of these organizations. Thirty-six percent of the peanut-allergic child participants and 22% of the peanut-allergic adult participants were recruited through such an association. Parents of peanut-allergic children recruited from this association indicated their children experienced more impairment in familial/social interaction when compared to parents of children recruited from the allergy clinic. There were so

few peanut-allergic adults recruited from the association that the comparison between them and peanut-allergic adults recruited elsewhere was inconclusive.

Atopic conditions other than peanut allergy may have influenced the quality of life and family relations of those suffering from peanut allergy. We were not able to effectively control for the presence of other atopic conditions because there was incomplete ascertainment of these conditions in the rheumatological disease group.

Until recently, peanut allergy had not been perceived by the parents of nonpeanut-allergic children, schools, physicians other than allergists, and the media as a condition presenting major problems for patients and their families. However, our findings indicate that this condition may indeed exert a profound impact. Our results also underscore the educational and emotional support that families of children with a peanut allergy may require. We believe that an important component of the problem results from the growing number of products adhering to good manufacturing practices and therefore labeling all possible peanut contaminated foods with 'may contain peanut.' Although this clearly advises the consumer of the potential for peanut contamination and thus minimizes the risk of accidental ingestion, it also greatly limits the availability of food products and creates a stressful milieu when suitable alternatives are not available. We would hope that the food industry would make a greater commitment to peanut free manufacturing and thus eliminate part of the stress resulting from dietary restrictions.

Our study also clearly demonstrates that 'labeling' a child as peanut-allergic can have major consequences on his and his family's life, reinforcing the need to make an accurate diagnosis. Correct diagnosis requires detailed history taking by an allergist about symptoms following peanut ingestion combined with skin testing and potentially a peanut challenge.

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